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Removing the Stress from Selecting Instruments: Arming Social Workers to Take Leadership in Routine Distress Screening Implementation

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Abstract

Quality cancer care requires identifying and addressing the psychosocial needs of cancer patients. Oncology social workers have long been on the forefront of this endeavor. Although there has been longstanding interest in screening cancer patients for distress, it has recently been included as a quality of care metric in institutions accredited by the American College of Surgeons. Implementing routine screening for distress in oncology settings requires thoughtful planning, including assessing various screening instruments and considering a host of variables within each practice setting. Oncology social workers are best positioned to provide leadership in operationalizing this mandate and to lead their team in the choice of a distress measure for compliance with the screening guideline. This article highlights the most popular distress screening measures used in oncology and their psychometric properties.

Keywords

distress screening implementation; distress screening in cancer patients; oncology social workers; social work leadership role

Oncology social workers (OSWs) have provided psychosocial support to cancer patients since the 1940s, having been “the first, alongside nurses, to attend to the psychological and social problems of cancer patients and their families” (Abrams, 1974; Holland, 2002, p. 214). Today, OSWs remain the primary professionals in the health care setting who provide psychosocial services to cancer patients and their significant others (Association of Oncology Social Work, 2001) and, as such, are essential members of the oncology team (Fobair, 2007; Hermann & Carter, 1994; Holland, 2002; Rohan & Bausch, 2009; Stearns, Lauria, Hermann, & Fogelberg, 1993). In recent years, the Institute of Medicine (IOM; 2008) recognized that quality cancer care requires identifying and addressing the psychosocial needs of cancer patients. To that end, the American College of Surgeons (ACoS) Commission on Cancer (CoC; 2012) required psychological distress screening for every cancer patient treated in ACoS-accredited facilities.

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This requirement heightens the importance of OSWs' proficiency in understanding and facilitating the administration of distress screening instruments. The current health care environment demands high caseloads and leaves limited time for an OSW to assess the myriad distress screening instruments, which is necessary if OSWs are to play an active role in determining which of these instruments to use and how to administer them. This article summarizes three commonly used instruments and discusses the strengths and weaknesses of each. The standards encourage institutions to use standardized, validated measures with established clinical cutoff scores; however, the standards also state that facilities are free to use any measure of their choice and determine their own cutoff score to identify distressed patients (CoC, 2012). The purpose of this article is to assist OSWs in the evaluation and selection of distress screening tools, and thus meet the CoC standards concerning distress screening.

ASSESSMENT OF DISTRESS SCREENING INSTRUMENTS

Evaluators of screening measures will most likely select instruments based on a balance of scientific evidence and the feasibility of implementing the instrument within a particular setting and with a particular patient population.

Scientific Criteria

Instruments are graded on their psychometric properties, that is, their ability to accurately and consistently measure the concept(s) of interest, in this case, distress. The National Comprehensive Cancer Network (NCCN; 2012), a nonprofit alliance of 21 leading comprehensive cancer centers in the United States, defines *distress* in cancer patients as a "multifactorial, unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment." Psychometric properties of measurement instruments are calculated mathematically and reported as reliability, validity, sensitivity, and specificity. In the sections to follow the psychometric properties of select measures are described plainly and specifically in relation to distress screening.

Reliability—*Reliability* refers to an instrument's ability to measure a concept over time, across individuals, and in different contexts. An important component of reliability is an instrument's internal consistency. If a measure is internally consistent, it means that different questions that measure the same concept are answered similarly by respondents. In other words, if three questions on a scale measure anxiety, but in different ways, a respondent should theoretically answer them similarly. Internal consistency is often measured and reported as Cronbach's alpha (α), a score that ranges from .0 to 1.0 (Cronbach, 1951). The closer to 1.0 the Cronbach's alpha score is, the more reliable the measure. An internal consistency of .8 or higher is generally considered acceptable (Vodermaier, Linden, & Siu, 2009). If planning to use an instrument repeatedly over time, or as a pre- and postintervention measure, it is important to select one for which published reports indicate that the measure reliably captures change over time. Finally, the ability of respondents to comprehend screening questions in terms of their reading level or cultural relevance also reflects upon the instrument's reliability. Instruments that have been

translated into languages other than English require their own psychometric evaluations and reporting of reliability statistics.

Validity—There are many ways to assess validity (e.g., face validity, content validity, concurrent validity, criterion validity, construct validity), but the overall definition is the degree to which an instrument actually measures what it intends to measure. For example, an instrument assessing symptoms of anxiety would not be a valid measure of depression because symptoms of anxiety are not necessarily indicative of depression. Similarly, if a measure of depression did not assess one's level of interest or pleasure in daily activities—a critical aspect of depression as defined by the *Diagnostic and Statistical Manual* (American Psychiatric Association, 2000)—then that proposed measure would not be considered a valid or useful measure of depression. Validity statistics indicate how well a measure captures the multiple and varied aspects of the concept it seeks to measure (construct validity). They also indicate the extent to which a measure correlates with other instruments assessing similar outcomes (concurrent validity). For example, given that depression is likely associated with poor quality of life, a valid measure of depression would likely be significantly correlated with a separate quality-of-life measure. As new instruments are developed and tested in the oncology setting, they are compared with other instruments (or techniques, such as a clinical interview) that have already been shown to be valid in measuring distress.

Sensitivity and specificity—Related to reliability and validity are sensitivity and specificity. Stated simply, *sensitivity* refers to the degree to which an instrument detects distress when it actually exists. *Specificity* refers to the degree to which an instrument accurately measures no distress when it does not exist. If a distress test is highly sensitive but not specific, it will detect distress in too many people, that is, those experiencing distress and also some who are not (false-positives). If a test lacks sensitivity but is highly specific, it will detect those with the highest levels of distress but will fail to detect distress in some others who are experiencing it (false-negative). Sensitivity and specificity scores are reported as decimals ranging from .0 to 1.0, with higher scores indicating more sensitivity or specificity (e.g., a sensitivity score of 1.0 indicates that an instrument, at a particular cutoff score, will identify 100% of distressed persons). In practical terms, a cutoff score used to indicate clinically-significant distress is calculated by determining the best balance of sensitivity and specificity statistics (Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; Jacobsen et al., 2005; Vodermaier et al., 2009).

Implementation Criteria

Implementation criteria speak to the practicality of using a measure in a clinical setting. These criteria encompass access to the measure, the ease of use of a measure, and the resources needed for scoring the measure. Although, undoubtedly, there are facility-specific issues (e.g., staffing availability) and population-specific issues (e.g., languages spoken by the patient population) that affect the practicality of implementing routine distress screening for oncology patients, there are important issues that must be considered across contexts. The analysis that follows first focuses on the scientific merits and the feasibility for

implementation of the distress measures most commonly applied in oncology and then summarizes the strengths and weaknesses of using each measure in a clinical setting.

INSTRUMENTS MOST COMMONLY USED IN ONCOLOGY SETTINGS

The instruments most commonly used in oncology settings are the Hospital Anxiety and Depression Scale (HADS), the Brief Symptom Inventory–18 (BSI-18), and the Distress Thermometer (DT). Each of these measures has an internal consistency (Cronbach's alpha score) of .8 or higher (Vodermaier et al., 2009). These instruments are characterized as ultrashort, short, and long or standard, based on number of items (questions) contained in or time needed to administer the instrument (Mitchell, Kaar, Coggan, & Herdman, 2008; Vodermaier et al., 2009).

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) is a short, 14-item self-report instrument that measures two domains (anxiety and depression) in physically ill (as opposed to psychiatric) patients, and takes 2 to 5 minutes to complete (Snaith, 2003). Each domain has seven items that measure symptomology within the last week, and severity scores range from 0 to 3 for each item. HADS scores are summed and range from 0 to 21 for each domain. A cutoff score of ≥15 for either anxiety or depression indicates distress that requires psychosocial intervention (Jacobsen et al., 2005). The HADS is available in a variety of languages (English, Spanish, Dutch, French, German, Swedish, Italian, Chinese, Japanese, Urdu, Hebrew, and Arabic) (Snaith, 2003) for a fee from ACER Psychology (Snaith & Zigmond, 2012).

Strengths and limitations—The HADS is generally reported to possess sound psychometric properties (Carlson & Bultz, 2003; Sellick & Edwardson, 2007; Vodermaier & Millman, 2011), with a majority of studies reporting sensitivity ranging from .70 to 1.00 and corresponding specificity ranging from .70 to .90 (Vodermaier et al., 2009). As such, the HADS has often been the measure against which other distress measures have been evaluated in cancer care (Akizuki et al., 2003; Baken & Woolley, 2011; Holland, 2002; Roth et al., 1998; Vodermaier & Millman, 2011). Additionally,, although, as noted, Jacobsen et al. (2005) recommend a cutoff scale of ≥15, instrument authors offer a more precise algorithm: 8 to 10 represent mild cases, 11 to 15 represent moderate cases, and ≥16 represent severe cases of anxiety or depression, which may assist OSWs in prioritizing follow-up with patients (Snaith & Zigmond, 2012). Another strength of the HADS is the variety of languages in which it is available, making it suitable for use with persons from a broad range of linguistic and cultural backgrounds. Importantly, HADS responses can be scored easily and used immediately in a clinical setting (Mitchell et al., 2008).

An important consideration and potential limitation of the HADS is the cost of obtaining the instrument for use in routine screening of all cancer patients.

Brief Symptom Inventory–18

The Brief Symptom Inventory–18 (BSI-18) is a short, 18-item self-report instrument that measures a patient's symptoms of somatization, depression, and anxiety over the past week.

The instrument takes approximately 2 minutes to administer (Derogatis, 2012). The BSI-18 provides a global severity index, indicative of an overall distress level. It can be administered via pencil and paper or with the PAD (Patient Assessment Device), a hand-held electronic device. The resources required for scoring vary greatly. Scoring can be accomplished locally (by hand, optical scan, or computer via the PAD) or remotely by faxing completed instruments to the publisher, who will process them within 2 hours of receipt and return them by fax. Zabora et al. offer an additive scoring mechanism and suggest using cutoff scores of ≥10 for men and ≥13 for women, or a global score of ≥63 for identifying cancer patients in need of psychosocial intervention (Bevans et al., 2011; Zabora et al., 2001). The BSI-18, including associated manuals and services, is available in English and Spanish for purchase from Pearson Assessments (Derogatis, 2012).

Strengths and limitations—The BSI-18 is consistently reported to have sound psychometric properties (Bevans et al., 2011; Carlson & Bultz, 2003; Vodermaier et al., 2009; Zabora, Diaz, & Loscalzo, 2003; Zabora & Knight, 2001), with cancer patient studies reporting sensitivity and specificity of .91 to .97 and .85 to .93, respectively (Zabora et al., 2001; Recklitis et al., 2006). The BSI-18 provides information on a patient's experiences across three domains (somatization, depression, and anxiety) in addition to a global score. Such detailed information is useful in the clinical setting, because it can help focus the formal psychosocial assessment. The BSI-18 has the capability to produce a progress report that displays a patient's scores on each of the domains for the past five administrations of the instrument. This report has obvious clinical utility, because a clinician can track a patient's distress scores over time.

Similar to the HADS, a limitation of the BSI-18 is the cost of obtaining the instrument and scoring the instrument (depending on the options chosen) for routine screening of all cancer patients. Furthermore, scoring can be complicated and, if done as the publisher suggests, cannot be used immediately in the clinical setting (e.g., to refer a patient to an OSW) without use of the PAD and its scoring/printing docking station. The complexity of the scoring algorithm is due to the ability to compare BSI-18 scores to established norms. It should be noted that this comparison ability is a strength of the BSI-18 in research applications but adds to the complexity of clinical applications. Consequently, the additive scoring mechanism noted previously (Zabora et al., 2001) can serve clinical settings more easily and efficiently.

Distress Thermometer

The Distress Thermometer (DT), developed by the NCCN, is an ultrashort, single-item self-report instrument that measures a patient's level of distress over the past week on an 11-point, visual analog scale (resembling a thermometer) that ranges from 0 (*no distress*) to 10 (*extreme distress*). A cutoff score of 4 is associated with an optimal balance of sensitivity and specificity and indicates need for further psychosocial assessment and referral or intervention (Jacobsen et al., 2005; Ransom, Jacobsen, & Booth-Jones, 2006). The DT is sometimes accompanied by a Problem List for patients to specify the source of their distress: practical problems, emotional concerns, family problems, nutrition problems, and spiritual/religious concerns.

Strengths and limitations—The brevity of the DT enhances its ease of use and limits the resources needed to score and interpret the results. DT results are immediately available for clinical use. Studies have shown that the DT can discriminate between cancer patients with and without clinically significant distress comparably to the HADS and the BSI-18 (Hoffman et al., 2004; Jacobsen et al., 2005). Another benefit of the DT is that it is available at no cost, after obtaining permission from the NCCN (2012). Finally, the DT has been successfully adapted for use across multiple languages and cultures (Absolom et al., 2011; Akizuki et al., 2003; Dolbeault, Boistard, Meuric, Copel, & Brédart, 2011; Grassi et al., 2011; Ito et al., 2011; Vodermaier et al., 2009) and is suitable to administer to low-literacy, often more vulnerable, patients.

There is evidence to suggest that the DT has only moderate specificity (ranging from .49 to .82) and thereby misses identifying some distressed patients (Vodermaier et al., 2009). However, in a recent meta-analysis of distress screening tools, Mitchell (2010) found that combining the use of the DT with the Impact Thermometer (IT) raised the sensitivity and specificity of the combined measure to .81 and .82, respectively. Furthermore, the use of the Problem List has been shown to increase the utility of the DT (Jacobsen et al., 2005; Kendall, Glaze, Oakland, Hansen, & Parry, 2011; Mitchell, 2010; Mitchell, Vahabzadeh, & Magruder, 2011) and can be used to help identify which provider can best address a patient's concerns, thereby facilitating referral to the appropriate type of professional (OSW or other psychosocial provider, dietician, chaplain, etc.).

CONSIDERATIONS FOR OSWS

Armed with the knowledge of the psychometric properties and feasibility of the HADS, BSI-18, and the DT, other issues that are important in the implementation of distress screening for cancer patients must be considered. First, it is essential to consider screening equally across cultures and populations. Who are we screening with these methods? Who are we missing? What do we need to do to ensure we are screening all populations we serve equally? The evidence suggests current distress screening may be missing the most vulnerable persons (Carlson & Bultz, 2003; Kayser, Acquati, & Tran, 2012). One notable point to mention is that racial disparities exist. Despite studies that have shown increased levels of distress in non-White cancer patients (Carlson & Bultz, 2003; Hoffman et al., 2004), racial disparities in screening for and treating distress still exist. For example, one study found Whites to be nearly 7 times more likely to be assessed for depression than non-Whites (Tai-Seale et al., 2005), and another found Whites to be more likely to be treated for depression than non-Whites (Tai-Seale, McGuire, Colenda, Rosen, & Cook, 2007). Furthermore, Whites are over-represented in many of the studies of the efficacy of distress screening in cancer patients (Carlson & Bultz, 2003; Hoffman et al., 2004; Kayser et al., 2012). The cultural aspects of distress screening are addressed in depth elsewhere in this special issue (Kayser et al., 2012).

Another point to consider is related to cutoff scores of screening instruments. As noted for each of the three instruments, cutoff scores have been established in the literature to maximize the sensitivity (true-positives) and specificity (true-negatives) for each measure. Adhering to published cutoff scores is important, because false-positives will generate

referrals to OSWs unnecessarily, whereas false-negatives will leave distressed patients without psychosocial intervention. Yet using an established cutoff score can generate more psychosocial referrals than current psychosocial staffing levels can respond to. How will your setting handle this dilemma? Is it ethical to screen for distress using published cutoff scores, but then not have sufficient staff to respond? On the other hand, is it ethical and wise to raise cutoff scores arbitrarily to make sure that only the most distressed patients reach the threshold to receive psychosocial services?

In clinical terms, the principal consideration is as follows: If we screen someone, are there the resources to help? Screening for distress is a necessary, but not sufficient, aspect of the endeavor to care for the psychosocial needs of oncology patients. The challenge is not only to incorporate routine distress screening into cancer care but also to meet the needs of patients who are distressed (CoC, 2012). Additionally, routine screening has been shown to shift psychosocial caseloads to a more diverse patient population with complex needs (Zabora et al., 2003). Meeting this increased need may necessitate expansion of social work roles and availability of services in some oncology health care settings. As Zabora and others (Cunningham, 1995; Zabora & Knight, 2001) have noted, psychosocial support can be provided in myriad ways, depending on the level of intervention needed by a particular patient. The least distressed patients may get their needs met through psychoeducational seminars or patient-to-patient support. More distressed patients may require crisis intervention, support groups, and/or short-term therapy. The most distressed patients generally require psychotherapy and family therapy (Zabora & Knight, 2001). OSWs, with their professional training, along with the profession’s longstanding experience in providing psychosocial care to cancer patients and their significant others, are well poised to respond and match services to service needs along this continuum.

If there are not enough OSWs to appropriately address the distress of patients in oncology settings, it will be more costly for the health care system in the long run. It is well documented that distressed patients incur more unnecessary medical costs than do patients who are not distressed because the former have “more difficulty making decisions, are more likely to miss appointments, are less adherent to their treatment regimens, and are less satisfied with their medical care” (Hoffman et al., 2004, p. 792; see also Bottomley & Hunton, 1996; Carlson & Bultz, 2003; and Holland, 1999). Routine distress screening of oncology patients, when accompanied by appropriate psychosocial treatment, is likely to not only improve the overall care of cancer patients but also maximize health care resources.

Finally, the context of the oncology delivery setting must be carefully considered prior to implementing a routine screening program. Although the CoC (2012) now requires screening for psychosocial distress for every cancer patient treated in ACoS-accredited facilities, it has not given specific guidance on how to do this. Facilities must decide for themselves which screening tool to use, at what intervals along the illness trajectory to screen patients, and what do to with the results of such screening. Studies have shown that the best way to enhance routine screening in oncology settings it to use an instrument that is acceptable not only to patients but also to providers (Absolom et al., 2011; Mitchell, 2010; Mitchell et al., 2008).

The current climate in health care recognizes what OSWs have historically known: that quality cancer care requires identifying and addressing the psychosocial needs of cancer patients (IOM, 2008). Planning for the implementation of screening entails knowing the efficacy of the distress screening instruments used in oncology settings, articulating a given instrument's strengths and weakness, assessing the needs and interests of staff at one's institution, knowing the context and needs of the facility's patient population, and, finally, arriving at consensus regarding how to best implement routine screening. OSWs have an excellent vantage point from which to play a leadership role in planning how to implement routine distress screening in their oncology care delivery settings.

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